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Bringing dying back home? – Northern Finns' end-of-life preparations, concerns and care preferences and Finnish care policy's emphasis on care at home[1]

Abstract

In recent years, Finnish care policy has emphasised that older people should remain at home for as long as possible. Since the final stages of life and death will theoretically happen more often in the home, it is important to identify people's experiences and needs regarding end-of-life care and dying. The aim of this article is to provide knowledge on these questions from the perspective of the Northern Finnish people (N=294). Statistical analysis was used with data gathered from a survey of a random sample. People's wishes for their end-of-life place and carers and their end-of-life plans and concerns, are analysed as part of a social and cultural construction of dying and end-of-life care. The results show that people do have end-of-life concerns and that they consider end-of-life planning important but that few preparations are actually made. In many instances, home is regarded as the best place for end-of-life care and dying, but care institutions are also regarded positively. Reliance on professional care is very strong, even though people hope to receive care from family members as well. The results are discussed in the light of Finnish care policy and end-of-life culture.

Keywords: advance care planning, end-of-life care, dying

Introduction

In traditional societies, death was part of everyday life. People prepared for it in the midst of their everyday lives and died in the places where they had spent their lives (Elias 1985). However, as societies started to modernize and the service sector began to grow, the last stages of life were transferred from homes to institutions such as hospitals and care homes. Death became isolated from everyday life and medicalized (Miettinen 2006).

[1] This study is part of a comparative end-of-life care research initiated by Sapporo City University (Kazuyo Sooudi and Midori Mimaya) and Hokkaido University (Reiko Takeu and Azusa Shikanai) and carried out by the aforementioned together with the University of Lapland. Supplementary questions were added to the Finnish questionnaire (e.g. concerning end-of-life preparations) by the Finnish research team (Marjaana Seppänen, Marjo Outila, Eeva Rossi, Heli Valokivi, Satu Peteri). The analysis of the data was conducted as part of 'A well-functioning home care to Lapland - Diverse forms of support to living at home' project funded by the Finnish Ministry of Social Affairs and Health. At an early phase of the analysis, help was received from statistics teacher Marianne Silen (University of Lapland).

In recent decades, the orientation of care for older people has changed from institutionalised care to care given at home. To enable people to live at home for as long as possible is currently the organizing principle of services in Finland. This became particularly clear in 2013 with a new 'Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons' (980/2012). From the beginning of 2015, the law was changed to promote a larger proportion of older adults residing in private homes. As an outcome of these reforms, it can be anticipated that the final stages of life will more often be spent at home—and due to the reduction in child mortality and improvements in medical care, death is most likely to be encountered after a long life in which illness has been part of life (Luptak 2004; Lloyd 2010).

Dying has mostly been approached as a medical and nursing issue, both in professional practice and in research (Brown and Walter 2014). As part of this tradition, death has been studied from the perspectives of the psychological processes experienced (e.g. Kübler-Ross 1969) and the care needed. The care of older persons has been examined from the perspective of both caregivers and care receivers in both informal and formal care contexts (e.g. Genet *et al*. 2011). As having older people in poor physical health and dying at home becomes a more regular part of the everyday life of families and home care services, the significance of the subject becomes greater. Providing information about psychosocial and cultural issues in the context of end-of-life care and death is a rare but important and growing research area (Donovan *et al*. 2011; Carr 2012; Bullock 2011; Ko *et al*. 2013). The understanding of death is culturally bound (Leishman 2009a), and the structures of society and the organization of responsibilities and practices relating to care define how the last stages of life and death are encountered (Gomes *et al*. 2011). Especially important are those practices that relate to the social and health services (Luptak 2004).

Theoretical point of view, research questions, data and method

The aim of this study was to provide knowledge about the end-of-life wishes, concerns, and preparations of the people of northern Finland as part of their socio-cultural construction of death and end-of-life care. We analysed our findings in the light of current thinking that Western culture is in a place where old age, especially the fourth age in which care and end-of-life issues are central, is culturally rejected and pushed away from normal social life (Higgs and Gillerad 2015; Elias 1985).

Elias (1985) suggests that we have been distanced from the aging process and from dying. He writes about the 'repression' of death, as one aspect of a more comprehensive movement in civilisations in which death is pushed more and more behind the scenes of everyday social life. Many people have difficulty in identifying with aging and death. For the dying, this means isolation and those close to the dying person often have difficulty in facing the prospect of death. Death and dying are spoken of less openly and less frequently. Elias writes that people are forced back onto their own resources, and into their own individual powers of invention, in dealing with, for example, emotions relating to dying. There are insufficient common expressions or standardized forms of behaviour to make it easy for people to confront emotionally challenging situations like dying. (Elias 1985.) Included in the socio-cultural constructions of old age and dying are perceptions of how we should act in relation to our own death; how we should prepare for it, and how we wish for or can rely on the help and care of others when our own death is near. Death as a social construction means that it is defined using words, concepts and ways of thinking that are available in the individual's culture; included

are ideas of change through time and the differences, for example, between individuals and social groups (Leishman 2009b; Kastenbaum 1998).

Our research questions are:

- What kind of end-of-life preparations, concerns and care preferences do people have?
- What can be said about the social exclusion of dying when thinking about people's end-of-life preparations, concerns and care preferences, and what implications may this have for care policy and practices?

Our research data consisted of responses from 294 people to a postal survey with a random sample. The aim of the survey was to gather information related to end-of-life care and dying.[2] The survey was sent to 1000 adults older than 20 years living in two cities in northern Finland, and the data was collected in December 2015. The selection of Rovaniemi and Sodankylä as the research areas was based on a Japanese-Finnish comparative study design: in both countries, two northern urban regions that are surrounded by a sparsely populated area were selected for study. The response rate was 29%. (See Table 2 for detailed information.)

Demographic variables in the survey were age, gender, household size, education, annual income, self-reported financial security and self-reported health. Probably due to the theme of the survey, over half of the respondents were 63 years of age or older. As compared to the general population of the area, respondents were more likely to be older, women, less likely to be living alone, and having a low income (19 999 euros or less, per household, per year).

The aim of the study was to form an overview of the respondents' thoughts and opinions; therefore the data were analysed by using descriptive statistics. The differences among variables were analysed by bivariate cross-tabulation, and the significance of differences between groups was evaluated using a chi-square test. Reported p-values were exact (2-sided).

Most research in the area of advanced care planning and end-of-life care is qualitative, using focus groups and interviews for gathering data (e.g. Bito 2007; Ko and Bergman 2012; Piers *et al*. 2013). This study contributes to the literature by using mainly quantitative methods and targeting a wider age range. Unlike many other studies, this survey did not target the older generations only, but all adult residents (20 years or older, with a mean of 62 years), and information was collected randomly rather than recruiting people from clinics or senior centres (versus Malcomson and Bisbee 2007; Lynn, Curtis and Lagerwey 2016; Brinkman-Stoppelenburg, Rietjens and van der Heide 2014).

At the end of the survey, respondents were asked to share their thoughts and experiences of home care, end-of-life care and dying. Eighty-three (28%) shared their thoughts on these topics. Extracts from these data are used in this article to reveal respondents' thoughts and feelings.

[2] There were 46 questions in the questionnaire, one of which was an open question. Examples of questions: Have you experienced someone close to you dying? Does thinking about the end-of-life worry you? If it does, what kind of worries do you have? Where would you like to spend the final stages of your life? From whom would you like to receive care at the end of life?

Ethical issues

The questionnaire and research plan were approved by the University of Lapland research ethics committee.

Results

End-of-life concerns

'More than death, I fear ending up in a breathing machine, or the like, lying and withering with the pain.'

Death causes worries and fears in people's lives, although the causes of their concerns may change over time (Elias 1985). In our study, more than half of the respondents had some kind of end-of-life concerns (Table 1). Respondents were most worried about the family that would be left behind. The possibility of pain, illnesses and suffering at the end-of-life also caused concerns. The qualitative study of Fleming *et al*. (2016) echoes these themes: the participants were not worried about death itself, but about the dying process and its impact on the persons who would be left behind. As in our study, the respondents hoped to die quickly and peacefully.

Table 1 Respondents' end-of-life concerns

	Thinking of end-of-life causes concerns %	Concern about death itself %	Concern over family %	Financial concerns %	Regret over unfinished things %	Other concerns %
% of all respondents	57	22.4	37.1	16.7	9.9	10.9
Female Male	58.2 55.4 p:0.633 χ2(1)=0.237	25.1 19 p:0.256 χ2(1)=1.526	38 35.5 p:0.713 χ2(1)=0.186	14.6 19 p:0.339 χ2(1)=0.993	8.8 11.6 p:0.552 χ2(1)=0.620	11.1 9.9 p:0.848 χ2(1)= 0.106
<63 yrs ≥63 yrs	61.2 53.1 p:0.189 χ2(1)=1.916	23.1 22.5 p:1.000 χ2(1)=0.014	45.4 30.6 p:0,011* χ2(1)=6.685	13.1 19.4 p:0.157 χ2(1)=2.060	13.8 5.6 p:0,024* χ2(1)=5.741	9.2 11.9 p:0.568 χ2(1)=0.525
Household 1 person 2 persons 3-6 persons	 45.8 56.3 73 p:0,004** χ2(2)=10.879	 20.5 22.9 25 p:0.825 χ2(2)=0.430	 19.3 36.8 59.4 p:<0.001*** χ2(2)=24.990	 15.7 13.2 23.4 p:0.176 χ2(2)=3.453	 7.2 6.9 18.8 p:0,020* χ2(2)=7.866	 10.8 11.1 9.4 p:0.938 χ2(1)=0.145
Financially Secure Insecure	 52 75.4 p:0.001** χ2(1)=11.494	 20 25.7 p:0.398 χ2(1)=1.004	 34 47.1 p:0.062 χ2(1)=3.825	 9.5 35.7 p:<0.001*** χ2(1)=26.122	 8 17.1 p:0,040* χ2(1)=4.663	 9 12.9 p:0.488 χ2(1)=0.857
Annual income per household -19 999 20-69 999	 50.6 61.8	 19 24.7	 24.1 45.6	 22.8 15.8	 8.9 10.8	 13.9 10.1

70 000-	59.5 p:0.255 $\chi 2(2)=2.719$	23.8 p:0.638 $\chi 2(2)=0.988$	33.3 p:0,004** $\chi 2(2)=10.781$	7.1 p:0.086 $\chi 2(2)=4.990$	11.9 p:0.891 $\chi 2(2)=0.325$	11.9 p:0.704 $\chi 2(2)=0.757$

*p<0.05
** p<0.01
*** p<0.001

Concerns about family left behind and regret about unfinished issues are less common among older than younger adults. Younger respondents (under 63, and henceforth referred to as younger adults) are generally more worried than the older adults (63 or older, and henceforth referred as older adults), although the difference is not statistically significant.[3] Most existing research suggests that concerns lessen as people age. Fear of death or death anxiety is less common among older adults than among younger adults (Cicirelli 2006; Chopik 2017; Fortner and Neimeyer 1999; Russac *et al*. 2007).

Our study did not confirm the connection between health problems and end-of-life concerns, which was contrary to other studies that have stressed that poor health and mental health problems are related to end-of-life concerns (Fortner and Neimeyer 1999; Hofer *et al*. 2017; Krause and Hayward 2015). One possible explanation for this is the low number of respondents who reported ill health.

Social support and being married can buffer fear of death (Chopik 2017; Hofer *et al*. 2017; Azeem and Naz 2015), but in our data, there was no significant difference regarding fear of death and dying between those who lived alone and those who lived with a partner or family members. However, respondents from bigger households were generally more worried than those living alone. Age mediated this result: 82.8% of people living in 3–6 person households were under 63. Unsurprisingly, respondents from bigger households were also more worried about family members than those living alone, and they had more regrets over unfinished issues. Additionally, our research suggests that financial insecurity has an impact on people's end-of-life concerns. People who reported themselves to be financially insecure had more concerns generally, both financial and regrets about unfinished issues. There was no difference in end-of-life concerns between the women and men in our study. Previous studies show contradictory results regarding the effect of gender on death anxiety (French, Greenauer and Mello 2017; Azeem and Naz 2015; Hofer *et al*. 2017; Fortner and Neimeyer 1999; Neimeyer *et al*. 2011; Russac *et al*. 2007).

Surprisingly, our study pointed out a negative connection between end-of-life concerns and preparations. One fourth of those with end-of-life concerns and 34% of those without concerns had made end-of-life preparations. These results were only tentative (p: 0.118), and a similar connection between concerns and the completion of an advance directive was not found. Do concerns limit people's ability or willingness to prepare?

End-of-life preparations

'I have made a living will. They are not going to keep me alive by force with tubes and with heavy pain medication.'

[3]The age groups were divided (<63 yrs and ≥63 yrs) based on the fact that 63 is a common retirement age in Finland.

In the light of end-of-life preparations, Elias' concept of people pushing death away seems accurate. In our study, only 29% of the respondents had made some preparations, and similar low numbers have been reported elsewhere (Clarke, Korotchenko and Bundon 2012). Financial arrangements seem to be the most common preparation made in both our and previous studies (Kelly, Masters and DeViney 2013; Samsi and Manthorpe 2011). Fourteen percent of our respondents had made a will, which was the most common single arrangement, and 8% had made burial or funeral arrangements. When looking at more care-related preparations, the proportions were not much bigger: 9.5% had completed an advance directive, 3% had a continuing power of attorney (which did not necessarily focus on care arrangements), and 2% of the respondents had made other care arrangements or had had care-related discussions.

Our analysis focused on the completion of an advance directive (AD), a document giving information about your wishes concerning end-of-life care, for example, medical treatment (e.g. resuscitation) and other care preferences. ADs are one aspect of advance care planning (ACP), which includes, for example, discussions with family and healthcare providers about future health-care. The aim of ACP is to clarify people's thoughts, hopes and values so that health and medical care decisions will reflect the person's views.

In our study, there was an inconsistency between attitude towards AD and the actual completion of it. Most respondents (79.4%) viewed an AD as necessary, but only 9.5% had completed it. Only 2.7% of the respondents viewed AD as unnecessary and 17.9% could not express an opinion on the subject.

A larger proportion of older adults as compared to younger adults had completed an AD. Also, living alone, having faced the death of a close person, having provided care at home and having cared for a dying person all increased the likelihood of having made an AD (Table 2).

Table 2 Characteristics of respondents and preparations for end-of-life

Demographic variables	Of all respondents %	Have an AD %	Other preparations %	Significance Chi-square –test AD= have an AD OP= other preparations
All respondents N=294		9.5	29.3	
<63 yrs ≥63 yrs	44.8 55.2	4.6 13.1	18.5 37.5	AD:0.014*, $\chi 2(1)=6.151$ OP:< 0.001***, $\chi 2(1)=12.635$
Female Male	59 41	11.1 7.4	31 27.3	AD:0.321, $\chi 2(1)=1.103$ OP:0.517, $\chi 2(1)=0.472$
Household 1 person 2 persons 3-6 persons	 28.5 49.5 22	 19.3 6.9 3.1	 39.8 28.5 18.8	 AD 0,001**, $\chi 2(2)=13.191$ OP:0,020*, $\chi 2(2)=7.821$
Financially Secure Insecure	 68 23.8	 9.5 10	 32.5 20	 AD:1.000, $\chi 2(1)=0.015$ OP:0.066, $\chi 2(1)=3.914$

Annual income per household				
-19 999	28.3	10.1	26.6	AD:0.074,
20 000-69 999	56.6	11.4	32.3	$\chi2(2)=5.181$
70 000-	15.1	-	21.4	OP:0.340, $\chi2(2)=2.217$
Education				
Basic	25.8	10.8	32.4	AD:0.691,
Vocational/secondary	36.6	10.5	19	$\chi2(2)=0.819$
Higher/university	37.6	7.4	36.1	OP:0,018*,
				$\chi2(2)=8.139$
Self-rated health				
Good	82.1	7.6	28	AD:0.160,
Bad	17.9	14.3	32.7	$\chi2(1)=2.280$
				OP:0.602, $\chi2(1)=0.425$
Experience of death of a loved one				
Experience	92.9	9.5	30	AD:1.000,
No experience	7.1	9.5	19	$\chi2(1)=0,000$
				OP:0.332, $\chi2(1)=1.138$
Child	5.8 (17)	17.6 (3)	47.1 (8)	AD:0.386,
				$\chi2(1)=1.382$
Sibling	22.1 (65)	16.9 (11)	36.9 (24)	OP:0.106, $\chi2(1)=2.765$
				AD:0.030*,
Spouse	14.3 (42)	19 (8)	42.9 (18)	$\chi2(1)=5.302$
				OP:0.164, $\chi2(1)=2.373$
Friend	18.4 (54)	16.7 (9)	29.6 (16)	AD:0.041*,
				$\chi2(1)=5.158$
				OP:0.044*,
				$\chi2(1)=4.383$
				AD:0.069,
				$\chi2(1)=3.917$
				OP:1.000, $\chi2(1)=0.005$
Experience in providing care at home				
Experience	45.2	13.5	30.8	AD:0,045*,
No experience	54.8	6.2	28	$\chi2(1)=4.532$
				OP:0.608, $\chi2(1)=0.291$
Providing care for a dying person				
Experience	34.8	15	35	AD:0.021*,
No experience	65.2	6.4	26.2	$\chi2(1)=5.632$
Professional experience	11.5	18.2	24.2	OP:0.135, $\chi2(1)=2.436$
Informal experience	20.2	13.8	39.7	

Numbers in brackets in the second column refer to the number of persons.
*$p<0.05$
** $p<0.01$
*** $p<0.001$

End-of-life issues may seem somewhat redundant for younger people in a society where death is far from everyday life. One of the respondents wrote: 'At the age of 27 it is difficult to think about the end of life period'. When people get older, the probability of facing the death of a family member or a friend increases, thus the probability of facing end-of-life care issues increases as well. As a result of this, it is more likely that people will come to think about their own end-of-life and perhaps make some arrangements for that. Our study reinforces the results of earlier studies on the effect of age: older adults' ACP exceeds the arrangements of younger adults. The statistical significance is stronger in other arrangements than in AD. Usually, ACP increases with age, but there are exceptions (Ke *et al*. 2017; Kelly, Masters and DeViney 2013; Lynn, Curtis and Lagerwey 2016; Shapiro 2015).

In the light of our study, living alone affects ACP. People who live in one-person households, especially older people, have more often made an AD and other end-of-life arrangements. This result parallels that of other studies. People who live alone with no relatives have a tendency to plan more than others. They may have no one who is eligible to act as their surrogates so they feel the need to plan ahead for themselves. (Samsi and Manthorpe 2011; Carr and Khodyakov 2007; Piers *et al*. 2011.)

Our analysis points in the direction that experiencing the loss of spouse, friend, child or sibling increases the likelihood of making an AD. Also, experience in providing care at home or for a dying person, especially in a professional setting, increases the likelihood of making an AD. It seems that close encounters with death prompt people to plan their own end-of-life. More research is needed to confirm these results, but according to existing research, facing the death of a close person increases the likelihood of making an AD (Carr and Khodyakov 2007; Piers *et al*. 2011; Kelly, Masters and DeViney 2013).

Prior studies have pointed out that people's health, education (contra Khosla, Curl and Washington 2016) and socioeconomic status also affect ACP. People with a poorer health status (Ke *et al*. 2017; Ko, Lee and Hong 2016; Lovell and Yates 2014), recent hospitalizations (Carr and Khodyakov 2007; Ke *et al*. 2017), or living in a care institution (Lynn, Curtis and Lagerwey 2016) are more likely to complete ADs. Analysis of our data indicated similar results, but because of the small proportion of people in our study who reported having trouble with their health, the analysis is only tentative. Contrary to other findings, our study did not affirm the impact of female gender (Ke *et al*. 2017; Lynn, Curtis and Lagerwey 2016), higher income level (Lynn, Curtis and Lagerwey 2016; Shapiro 2015; Khosla, Curl and Washington 2016) or higher educational level (Kelly, Masters and DeViney 2013; Lynn, Curtis and Lagerwey 2016) on greater engagement with ACP. Higher education seems to have some effect on other arrangements, but not on AD. However, economic security had some effect on making arrangements other than completing an AD. Those who felt financially secure had more often made end-of-life arrangements than those who felt financially insecure, although the difference was not statistically significant.[4]

Despite the generally positive attitude towards AD (Table 2), advance care planning is still quite rare (see also Ko and Berkman 2012). Prior research has found several reasons for this that seem to be in line with Elias' (1985) concepts involving the absence and subsequent rejection of death and old age in everyday life. ACP is seen as unpleasant and hostile (Jeong,

[4] According to previous studies (e.g. Bullock 2011; Ko and Berkman 2012) religion and cultural or ethnic background also impact ACP. Our survey did not cover those aspects.

Higgins and McMillan 2011), fearsome or upsetting (Malcomson and Bisbee 2009), a thing that has not even come into one's mind, a thing for which the time has not yet come (Simon *et al*. 2015), something that does not need to be done or else is ineffective (Brinkman-Stoppelenburg, Rietjens and van der Heide 2014; Ke *et al*. 2017).

There is research evidence that questions the effectiveness of ADs (Shapiro 2015) but there is also evidence for the positive effects of ACP, even though not actualized as planned (Sudore and Fried 2010). It has been said that ACP leads to a different level of appreciation of one's personal entity and transcendence (Jeong, Higgins and McMillan 2011), while also giving doctors an increased level of knowledge regarding their patients' wishes. Existing research suggests that people usually need support in order to make an ACP (Simon, Porterfield and Raffin 2015; Malcomson and Bisbee 2009; Lovell and Yates 2014). It seems that some older people are ready to discuss end-of-life issues and make end-of-life plans but that the opportunities to do so are lacking (Malcomson and Bisbee 2009; Ko, Lee and Hong 2016; Sharp *et al*. 2013). In order for the support to be effective, it must consist of information with concerted action, or interactive and informative interventions (Jeong, Higgins and McMillan 2011; Ko, Lee and Hong 2016; Freytag and Rauscher 2017).

In our study, the overall proportion of people that had made end-of-life preparations (Table 2) seemed small compared to the concerns that people reported (Table 1). People do have end-of-life concerns, they feel the need to plan their care, but few preparations are made.

Preferences for place of end-of life care

'If I were in my right mind and could move about relatively well, I would absolutely live at home the final stage. But if I had dementia, were paralyzed, all drugged up, or otherwise a so-called "difficult" case, there's no way I would like to be in home care – the family would probably suffer too.'

Some of the most central issues in end-of-life care are wishes regarding end-of-life place and carers. More than half of the respondents in our study preferred to spend their end-of-life period at home (Table 3). Prior research shows that home is usually the place where people prefer to receive end-of-life care (Choi *et al*. 2010) and die (Beccaro *et al*. 2006; Choi *et al*. 2010). The proportion of people choosing home over an institution varies, but commonly it is well over 50 percent (Hunt, Shlomo and Addington-Hall 2014a; Hunt, Shlomo and Addington-Hall 2014b; Gott *et al*. 2004; Hoare *et al*. 2015; Gomes *et al*. 2013).

Table 3 Respondents' preferences for place at the end-of-life

	Home %	Hospital %	Care home %	Hospice %	Significance %
All	57	4	24.2	14.8	
Female Male	53.5 61.2	4.4 3.4	22.6 26.7	19.5 8.6	p:0.083 $\chi 2(3)=6.643$
<63 yrs ≥63 yrs	73.2 44	- 7.3	17.1 30	9.8 18.7	p:<0.001*** $\chi 2(3)=27.417$
Household 1 person	44	6.7	29.3	20	p:0.004**

2 persons	53.7	4.4	25	16.9	$\chi 2(6)=19.207$
3-6 persons	77.8	-	17.5	4.8	
Self-reported health					
Good	62.6	3.3	19.4	14.7	p:0.024*
Bad	40.8	6.1	36.7	16.3	$\chi 2(3)=9.347$
Annual income per household					
-19 999	48.6	7.1	30	14.3	p:0.059
20-69 999	58.4	2.6	24	14.9	$\chi 2(6)=12.051$
70 000-	75.6	2.4	7.3	14.6	
Education					
Basic	41.8	7.5	40.3	10.4	p:0.005**
Vocational/secondary	61.4	4	16.8	17.8	$\chi 2(6)=18.404$
Higher/university	63.1	1.9	20.4	14.6	

*p<0.05
** p<0.01
*** p<0.001

In our study, the biggest difference in place preference was between the age groups. Older adults preferred an institution more often than younger adults. Prior research has shown diverse results for the effect of age. Sometimes, older age groups prefer home as the place of death more than younger people (Gomes and Higginson 2008; Sanjo *et al*. 2007), but sometimes it is the other way around (Foreman *et al*. 2006). Previous research also points out that the preferred place for end-of-life care might differ from the preferred place for dying. Even though people may not prefer to have care at home, they may prefer to die at home (Aoun and Skett 2013).

Another significant variable was household size: people living alone preferred an institution over home more often than people living with others (see also Iecovich, Carmel and Bachner 2009). Aoun and Skett's study (2013) with terminally-ill people who lived alone reveals that home may not always be the preferred location for end-of-life care or death. It may be that people who live alone prefer care institutions because they do not think it will possible to rely on professional care at home to the extent that living at home would be possible in the absence of a spouse, children or other informal caregivers. In accordance with Aoun and Skett's research (2013), health also affected respondents' preferences: less than half of the respondents who reported ill health chose home for their end-of-life place. Of the healthy respondents, over sixty percent chose home. Some expressed firmly their desire to stay in an institution if the circumstances were rough: 'If I get a memory sickness, I, at least, hope to get to a place where there is around-the-clock surveillance. In the final stage of cancer, [I would choose] terminal care in a hospital or in hospice if there is one.'

Cross-tabulation of age, size of household and preferred end-of-life place confirmed that age is a stronger predictor of preference for an institution than household size: among all the household categories, over half of the older adults preferred institutions. Among younger adults, it was the other way around: regardless of the household size, over half preferred home.

Educational background and economic situation are, to some extent, also connected with preference: a larger percentage of respondents with a lower annual income and lower education preferred an institution over the home. The difference was significant only for educational background. It is to be noted that 81.9% of the respondents with basic education only were older adults. Self-reported financial security did not affect preferences. In our study, there were

no differences between genders, in contrast to, for example, the studies of Choi *et al*. (2010) and Foreman *et al*. (2006) in which men preferred end-of-life care and dying at home more often than women did.

The issues that respondents raised in their responses dealt with the challenges of living at home, such as loneliness and lack of safety, but also the possibility of making one's own choices in one's own home. In spite of the general desire to spend the end-of-life at home, being at home raised mixed thoughts and feelings. Over 80% of the respondents would, to some extent, be happy if their family took care of them. At the same time, over 60% felt that they would be a burden on their families.

A theme frequently commented on in the responses was the state of professional care. People were worried that the resources for home care were insufficient and that there was a lack of psychosocial support and pain relief. Comments on the care received in hospitals, care homes and hospices were twofold: on one hand, people were very pleased, for example, with the care their family members had received, but on the other hand, they were very critical of the way that people were treated and left alone. It is worth noting that the perception of providing care at home was related to the wish to remain at home until the end of life. A bigger proportion (76.8%) of those who wanted to remain at home had a good picture of home care than those people who wished to spend their end-of-life in a care institution (60.9%) ($p:0.005$, $\chi 2(1)=7.952$).

Researchers have pointed out the inconsistency between the wish to die at home and the actual number of deaths occurring in institutions (Hunt, Shlomo and Addington-Hall 2014a; Bell, Somogyi-Zalud and Masaki 2009). The percentage of people dying in institutional settings is still high in Finland (according to Aaltonen [2015], 85.5% died in institutions in 2008) and in Europe, but there does seem to be a decreasing trend towards choosing a hospital death in Western societies (Houttekier *et al*. 2011; Gomes, Calanzani and Higginson 2011; Flory *et al*. 2004). However, despite the growing trend towards the support of home care, the relatively large proportion of people still preferring formal care in an institutional setting should not be dismissed.

People have different preferences for their end-of-life place, thus the heterogeneity of individual wishes should be acknowledged. Existing research stresses that there is a general lack of knowledge regarding people's preferences. This confirms Elias' (1985) notion of the exclusion of death and end-of-life issues: end-of-life and dying are difficult topics to discuss. This causes problems in achieving a good quality ACP, for people's well-being and for the actualization of their preferences (Badrakalimuthu and Barclay 2014; Raz, Shalev and Amit 2011; Hunt, Shlomo and Addington-Hall 2014a). Therefore, the starting point for a good ACP should be an awareness of the person's wishes and the way that they feel about care, for example the sharing of care responsibilities between family members.

Preferences for end-of-life carers

'What scares me most in aging is that I don't have any children. Who will truly attend to my interests when I am dependent on others' help?'

In addition to end-of-life place preferences, respondents were asked about their carer preferences. The carers most preferred were health care professionals; the next most preferred carers were spouse and children (Table 4).

Table 4 Respondents' preferences for end-of life carers

Demographic variables	Health care professionals %	Spouse %	Daughter %	Son %	Friend %
All respondents	77.6	54.8	38.1	35.4	9.9
Female	78.9	48.5	40.4	39.2	14
Male	75.2	63.6	34.7	29.8	4.1
	p:0.480	p:0,012*	p:0.392	p:0.107	p:0.005**
	$\chi2(1)=0.567$	$\chi2(1)=6.521$	$\chi2(1)=0.957$	$\chi2(1)=2.759$	$\chi2(1)=7.768$
<63 yrs	80.8	63.8	39.2	36.9	16.2
≥63 yrs	75.6	48.1	36.9	33.8	4.4
	p:0.321	p:0,009**	p:0.716	p:0.621	p:0.001**
	$\chi2(1)=1.104$	$\chi2(1)=7.167$	$\chi2(1)=0.169$	$\chi2(1)=0.317$	$\chi2(1)=11.408$
Household					
1 person	72.3	21.7	36.1	36.1	10.8
2 persons	78.5	66	34	27.8	6.3
3-6 persons	84.4	70.3	50	51.6	17.2
	p:0.210	p:<0.001***	p:0.082	p:0.004**	p:0.054
	$\chi2(2)=3.113$	$\chi2(2)=50.093$	$\chi2(2)=4.988$	$\chi2(2)=10.990$	$\chi2(2)=6.007$
Annual income per household					
-19 999	68.4	38	32.9	26.6	10.1
20 - 69 999	80.4	62	38.6	38	10.1
70 000-	85.7	71.4	38.1	35.7	11.9
	p:0.044*	p:<0.001***	p:0.699	p:0.208	p:0.962
	$\chi2(2)=6.208$	$\chi2(2)=16.812$	$\chi2(2)=0.763$	$\chi2(2)=3.066$	$\chi2(2)=0.121$

*p<0.05
** p<0.01
*** p<0.001

The responses reflect a strong reliance on professional care and a mindset in which the roles of family members and formal caregivers are clearly separated: 'I think that I would feel safer in the care of professionals who have familiarized themselves with palliative care, in a home-like environment; loved ones and family members by my side as friends, not as my carers.' It seems that people expect society to take care of its members: 'Society cannot expect family or friends to accept taking care of the end-of-life care. They have their own life.' Even though the majority of the respondents preferred to have health care professionals as their carers, there was also distrust towards them. For example one of the respondents wrote: 'The alternative [to staying at home] is the current lying drugged up and abandoned in a hospital ward or lying in your own waste in a commercial elderly home.'

Despite the preference for professional care, over half also preferred a spouse and about one-third a child as a caregiver. Men, more often than women, wished to receive care from their spouse. This was an exception to our otherwise fairly gender neutral results. In addition to a bigger proportion of males, younger adults, people living in bigger households and people with a higher income wished for their spouse to be their caregiver.

The preferences and comments of respondents can be interpreted as part of the institutionalization and medicalization of end-of-life care: dying in hospitals and care homes in the care of health care professionals is familiar. This is accompanied by individualization and an emphasis on individuals' independence: receiving care from family members is not an obvious preference (Elias 1985).

Discussion

Kastenbaum (1995) (cited in Cicirelli 2006, p.39) refers to the death system of each culture, meaning the people, places, objects, symbols and times that are related to death and dying. In the light of this study, the Finnish death system is strongly linked to health care professionals and formal institutions. There is a strong reliance on formal care, and death is hidden away in institutions such as hospitals and care homes. On the other hand, death-related issues are connected to the closest family members. People worry about and to some extent hope for care from their family members, but there is lack of discussion in families involving planning for end-of-life care and dying. Preparing for the end-of-life is viewed as an appropriate thing in itself, but in reality few make tangible preparations, despite their concerns related to death and end-of-life care. These results reflect Elias' (1985) notion of ageing and dying being pushed behind the social scene and away from everyday life, with an absence of readily used expressions and practices that would help people deal with end-of-life issues.

Changes in the political governance of end-of-life care are about to introduce change into the system for dealing with death in Finland. What kind of cultural change will they bring? Will they take into account the fears and concerns that people have towards dying and end-of-life care? Will they support people in vulnerable situations who have different concerns, poor health or financial struggles, all of which can make facing death harder, and who feel more need for support than the average person?

The implications of our study are two-fold for care policy: First, the concerns that people have in relation to end-of-life suggest that there is a need for support in completing ACPs. People feel the need to plan but the lack of readily accessible practices to complete an ACP leads to the situation where for many people it is left undone. The suggestion that there should be increased ACP planning is supported by existing research which provides evidence for its usefulness. ACP planning increases the probability of making people's end-of-life preferences known and respected (although this is not always possible), and the ACP has the potential to increase the well-being of people who engage with it (Hunt, Shlomo and Addington-Hall 2014a).

From the perspective of social and health care development, it should be noted that the support people have in their end-of-life planning comes, most frequently, from lawyers and financial planners (Simon, Porterfield and Raffin 2015; Malcomson and Bisbee 2009). However, people have other concerns in addition to financial ones, and for these it may be that social and health care professionals are the natural source of support. The development of Western societies has led to a situation where people face death relatively alone, and in places where they are unable to avoid the experience (Elias 1985). The need for support may continue to grow if the direction of social development continues as it is. In Finland, there are signs of change: for example, there is a growing interest in integrating ACP into older adults' care services.

Our second suggestion relates to the fairly large consensus that home is the best place to live, to receive care and to die (see e.g. Sepperd, Wee and Strauss 2011; Jeppson-Grassman and Whitaker 2007). Our analysis suggests that there is a need to investigate more closely the risks of pushing this idea further. Even though many people want to spend their end-of-life at home, according to our study, this wish is not entirely evident. In some life situations, people clearly prefer institutional settings for their end-of-life care, while those people who do wish to stay at home as long as possible still have a strong need for and reliance on formal care. These results suggest that people's preferences may differ significantly from political care guidelines that are increasingly stressing informal care (Heikkinen 2017). The risks of isolation, loneliness, insecurity and excessive pressure on families must be noted.

References

Aaltonen, M. (2015) *Patterns of care in the last two years of life. Care transitions and places of death of old people.* Acta Electronica Universitatis Tamperensis 1588. Tampere: Tampere University Press.

Aoun, S.M., & Skett, K. (2013) A longitudinal study of end-of-life preferences or terminally-ill people who live alone. *Health and Social Care in the Community*, 21, 530–535 (2013). doi:10.1111/hsc.12039.

Azeem, F., & Naz, M.A. (2015) Resilience, death anxiety, and depression among institutionalized and noninstitutionalized elderly. *Pakistan Journal of Psychological Research*, 30(1), 111–130.

Badrakalimuthu, V., & Barclay, S. (2014) Do people with dementia die at their preferred location of death? A systematic literature review and narrative synthesis. *Age and Ageing*, 43, 13–19 (2014). doi:10.1093/ageing/aft151.

Beccaro, M., Costantini, M., Rossi P. G., Miccinesi G., Grimaldi M., Bruzzi, P. (2006) Actual and preferred place of death of cancer patients. Results from the Italian survey of the dying of cancer (ISDOC). *Journal of Epidemiology and Community Health,* 60, 412–416 (2006). doi:10.1136/jech.2005.043646.

Bell, C.L., Somogyi-Zalud, E., Masaki, K.H. (2009). Methodological review: measured and reported congruence between preferred and actual place of death. *Palliative Medicine*, 23, 482–490 (2009). doi:10.1177/0269216309106318.

Bito, S., Matsumura, S., Singer, M.K., et al. (2007). Acculturation and end-of-life decision making: comparison of Japanese and Japanese-American focus groups. *Bioethics*, 21, 251–262 (2007). doi:10.1111/j.1467-8519.2007.00551.x

Brinkman-Stoppelenburg, A., Rietjens, J.A., Van Der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine,* 28, 1000–1025 (2014). doi:10.1177/0269216314526272.

Brown, L., & Walter, T. (2014). Towards a social model of end-of-life care. *British Journal of Social Work*, 44, 2375–2390 (2014). doi:10.1093/bjsw/bct087.

Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7, 83–98 (2011). doi:10.1080/15524256.2011.548048.

Carr, D., & Khodyakov, D. (2007). End-of-life health care planning among young-old adults: An assessment of psychosocial influences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62, S135–S141 (2007). doi:10.1093/geronb/62.2.S135.

Carr, D. (2012). Racial and ethnic differences in advance care planning: identifying subgroup patterns and obstacles. *Journal of Aging and Health*, 24, 923–947 (2012). doi: 10.1177/0898264312449185.

Choi, J., Miyashita, M., Hirai, K., Sato, K., Morita, T., Tsuneto, S., Shima, Y. (2010). Preference of place for end-of-life cancer care and death among bereaved Japanese families who experienced home hospice care and death of a loved one. *Supportive Care in Cancer*, 18, 1445–1453 (2010). doi:10.1007/s00520-009-0767-3.

Chopik, W.J. (2017). Death across the lifespan: Age differences in death-related thoughts and anxiety. *Death studies* 41, 69–77 (2017). doi:10.1080/07481187.2016.1206997.

Cicirelli, V.G. (2006). *Older adult's views on death.* New York: Springer.

Clarke, L.H., Korotchenko, A., Bundon, A. (2012). 'The calendar is just about up': older adults with multiple chronic conditions reflect on death and dying. *Ageing and Society*, 32, 1399–1417 (2012). doi:10.1017/S0144686X11001061.

Donovan, R., Williams, A., Stajduhar, K., Brazil, K., Marshall, D. (2011). The influence of culture on home-based family caregiving at end-of-life: A case study of Dutch reformed family care givers in Ontario, Canada. *Social Science & Medicine*, 72, 338–346 (2011). doi:10.1016/j.socscimed.2010.10.010.

Elias, N. (1985) *The loneliness of dying* (trans: Jephcott E.) New York: Blackwell.

Fleming, J., Farquhar, M., Cambridge City over-75s Cohort (CC75C) study collaboration, Brayne, C., Barclay S. (2016). Death and the Oldest Old: Attitudes and Preferences for End-of-Life Care - Qualitative Research within a Population-based Cohort Study. *PLoS One*. doi: 10.1371/journal.pone.0150686.

Flory, J., Yinong, Y.X., Gurol, I., Levinsky, N., Ash, A., Emanuel, E. (2004). Place of death: U.S. trends since 1980. *Health Affairs*, 23(3), 194–200.

Foreman, L.M., Hunt, R.W., Luke, C.G., Roder, D.M. (2006). Factors predictive of preferred place of death in the general population of South Australia. *Palliative Medicine*, 20, 447–453 (2006). doi:https://doi.org/10.1191/0269216306pm1149oa.

Fortner, B.V., & Neimeyer, R. (1999). Death anxiety in older adults: a quantitative review. *Death Studies*, 23, 387–411 (1999). doi:10.1080/074811899200920.

French, C., Greenauer, N., & Mello, C. (2017). A multifactorial approach to predicting death anxiety: assessing the role of religiosity, susceptibility to mortality cues, and individual differences. *Journal of social work in end-of-life & palliative care*, 13(2-3), 151–172. doi:10.1080/15524256.2017.1331181.

Freytag, J., & Rauscher, E.A. (2017). The importance of intergenerational communication in advance care planning: generational relationships among perceptions and beliefs. *Journal of Health Communication*, 22, 488–496 (2017). doi:10.1080/10810730.2017.1311971.

Genet, N., Boerma, W.G.W., Kringos, D.S., Bouman, A., Francke, A.L, Fagerström C. et al. (2011). Home care in Europe: a systematic literature review. *BMC Health Service Research.* 30,11, 207. doi:10.1186/1472-6963-11-207.

Gomes, B., & Higginson, I.J. (2008). Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine*, 22, 33–41 (2008). doi:10.1177/0269216307084606.

Gomes, B., Calanzani, N., Higginson, I.J. (2011). Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliative Medicine*, 26, 102–107 (2011). doi:10.1177/0269216311432329.

Gomes, B., Calanzani, N., Gysels, M., Hall, S., Higginson, I.J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care,* doi:10.1186/1472-684X-12-7.

Gott, M., Seymour, J., Bellamy, G., Clark, D., Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, 18, 460–467 (2004). doi:10.1191/0269216304pm889oa.

Heikkinen, A. (2017). Kuoleman kohtaamisen paikka. Master's thesis. Social work. Rovaniemi: University of Lapland.

Higgs P. & Gilleard C. (2015) *Rethinking Old Age. Theorising the Fourth Age.* London: Palgrave Macmillan.

Hoare, S., Morris, S.Z., Kelly, M.P., Kuhn, I., Barclay, S. (2015). Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *Plos one.* doi: 10.1371/journal.pone.0142723.

Hofer, J., Busch, H., Šolcová, I.P., Tavel, P. (2017). Relationship between subjectively evaluated health and fear of death among elderly in three cultural contexts. *International Journal of Aging & Human Development*, 84, 343–365 (2017). doi:10.1177/0091415016685331.

Houttekier, D., Cohen, J., Surkyn, J., Deliens, L. (2011). Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health*. doi:10.1186/1471-2458-11-228.

Hunt, K.J., Shlomo, N., Addington-Hall, J. (2014a). End-of-life care and achieving preferences for place of death in England: Results of a population-based survey using the VOICES-SF questionnaire. *Palliative Medicine,* 28, 412–421 (2014). doi:10.1177/0269216313512012.

Hunt, K.J., Shlomo, N., Addington-Hall, J. (2014b). End-of-life care and preferences for place of death among the oldest old: Results of a population-based survey using VOICES-Short Form. *Journal of Palliative Medicine*, 17, 176–182 (2014). doi:10.1089/jpm.2013.0385

Iecovich, E., Carmel, S., Bachner, Y.G. (2009). Where they want to die: correlates of elderly persons' preferences for death site. *Social Work in Public Health*, 24, 527–542 (2009). doi:10.1080/19371910802679341.

Jeong, S.Y., Higgins, I., McMillan, M. (2011). Experiences with advance care planning: older people and family members' perspective. *International Journal of Older People Nursing*, 6(3), 176–186.

Jeppson-Grassman, E. & Whitaker, A. (2007). End of life and dimensions of civil society: The Church of Sweden in a new geography of death. *Mortality*, 12, 261–280 (2007). doi:10.1080/13576270701430635.

Kastenbaum, R.J. (1998). *Death, Society, and Human Experience.* New York**:** Routledge.

Ke, L.-S., Huang, X., Hu, W.-Y., O'Connor, M., Lee, S. (2017). Experiences and perspectives of older people regarding advance care planning: A meta-synthesis of qualitative studies. *Palliative Medicine,* 31, 394–405 (2017). doi:10.1177/0269216316663507.

Kelly, C.M., Masters, J.L., DeViney, S. (2013). End-of-life planning activities: an integrated process. *Death Studies,* 37, 529–551 (2013). doi:10.1080/07481187.2011.653081

Khosla, N., Curl, A.L., Washington, K.T. (2016). Trends in engagement in advance care planning behaviors and the role of socioeconomic status. *The American Journal of Hospice and Palliative Care.* 33, 651–657 (2016). doi: 10.1177/1049909115581818.

Ko, E. & Berkman, C.S. (2012). Advance directives among Korean American older adults: knowledge, attitudes, and behavior. *Journal of Gerontological Social Work* 55, 484–502 (2012). doi: 10.1080/01634372.2012.667523.

Ko, E., Cho, S., Perez, R.L., Yeo, Y., Palomino, H. (2013). Good and bad death: Exploring the perspectives of older Mexican Americans. *Journal of Gerontological Social Work,* 56, 6–25 (2013). doi:10.1080/01634372.2012.715619.

Ko, E., Lee, J., Hong, Y. (2016). Willingness to complete advance directives among low-income older adults living in the USA. *Health & Social Care in the Community,* 24, 708–716 (2016). doi:10.1111/hsc.12248.

Krause, N. & Hayward, D.R. (2015). Acts of Contrition, Forgiveness by God, and Death Anxiety Among Older Mexican Americans. *The International Journal for the Psychology of Religion*, 25, 57–73 (2015). doi:10.1080/10508619.2013.857256.

Kübler-Ross, E. (1969). *On Death and Dying*. New York: Macmillan.

Leishman, J.L. (2009a). Introduction. In J.L. Leishman (Ed.), *Perspectives on Death and Dying* (pp. 1–13). Keswick: M&K Publishing.

Leishman, J.L. (2009b). Death, social change and lifestyle in UK. In J.L. Leishman (Ed.), *Perspectives on Death and Dying* (pp. 65–79). Keswick: M&K Publishing.

Lloyd, L. (2010). End-of-Life Issues. In D. Dannefer & C. Phillipson (Ed.), *The SAGE Handbook of Social Gerontology* (pp. 618-629). London: Sage.

Lovell, A. & Yates, P. (2014). Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012. *Palliative Medicine*, 28, 1026–1035 (2014). doi:10.1177/0269216314531313.

Luptak, M. (2004). Social work and end-of-life care for older people: A historical perspective. *Health & Social Work*, 29(1), 7–15.

Lynn, T., Curtis, A., Lagerway, M.D. (2016). Association between attitude toward death and completion of advance directives. *OMEGA—Journal of Death and Dying*, 74, 193–211 (2016). doi:10.1177/0030222815598418.

Malcomson, H. & Bisbee, S. (2009). Perspectives of healthy elders on advance care planning. *Journal of American Academy Nurse Practitioners*, 21, 18–23 (2009). doi:10.1111/j.1745-7599.2008.00369.x.

Miettinen, S. (2006). *Eron aika. Tyttärien kertomuksia ikääntyneen vanhemman kuolemasta.* Yhteiskuntapolitiikan laitoksen tutkimuksia 4. Helsinki: Yliopistopaino.

Neimeyer, R.A., Currier, J.M., Coleman, R., Tomer, A., Samuel, E. (2011). Confronting suffering and death at the end of life: The impact of religiosity, psychosocial factors, and life regret among hospice patients. *Death Studies*, 35, 777–800 (2011). doi:10.1080/07481187.2011.583200

Piers, R.D., Van Eechoud, I.J., Van Camp, S., Grypdonck, M., Deveugele, M., Verbeke, N.C. et al. (2011). Advance care planning in terminally ill and frail older persons. *Patient Education and Counselling*, 90, 323–329 (2011). doi:10.1016/j.pec.2011.07.008.

Raz, M., Shalev, C., Amit, S. (2011). Dying of 'old age' in Israel. *The European Legacy*, 16, 363–375 (2011). doi:10.1080/10848770.2011.575599

Russac, R.J., Gatliff, C., Reece, M., Spottswood, D. (2007). Death anxiety across the adult years: An examination of age and gender effects. *Death Studies*, 31, 549–561. doi:10.1080/07481180701356936

Samsi, K. & Manthorpe, J. (2011). "I live for today": a qualitative study investigating older people's attitudes to advance planning. *Health and Social Care in the Community,* 19, 52–59 (2011). doi:10.1111/j.1365-2524.2010.00948.x.

Sanjo, M., Miyashita, M., Morita, T., Hirai, K., Kawa, M., Akechi, T., et al. (2007). Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Annals of Oncology*, 18, 1539–1547 (2007). doi:10.1093/annonc/mdm199.

Sepperd, S., Wee, B., Strauss, S.E. (2011). Hospital at home: home-based end of life care. *The Cochrane Database of Systematic Reviews.* doi:10.1002/14651858.CD009231.

Shapiro, S.P. (2015). Do Advance directives direct? *Journal of Health Politics, Policy and Law*, 40, 487–530 (2015). doi:10.1215/03616878-2888424.

Sharp, T., Moran, E., Kuhn, I., Barclay, S. (2013). Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *The British Journal of General Practice*, 63, e657–e668 (2013). doi:10.3399/bjgp13X673667.

Simon, J., Porterfield, P., Bouchal, S.R. (2015). 'Not yet' and 'Just ask': barriers and facilitators to advance care planning—a qualitative descriptive study of the perspectives of seriously ill, older patients and their families. *BMJ Supportive & Palliative Care* 5, 54–62 (2015). doi:10.1136/bmjspcare-2013-000487.

Sudore, R.L., & Fried, T.R. (2010). Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Annals of Internal Medicine*, 153, 256–261 (2010). doi:10.7326/0003-4819-153-4-201008170-00008.